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ABSTRACT

the position statements of the Association for Retarded Citizens address major issues in early intervention for preschool age children with possible handicaps. Among statements offered are that public support should be maintained in maternal and child health block grant and in preschool incentive grants and demonstration programs; that multi-faceted screening programs should be available to all children at birth; that categorical labeling should be postponed until there is adequate proof of a specific condition; that a variety of services should be available to young at-risk and developmentally delayed children and their families; that parents should be afforded the opportunity to become involved in the intervention program; and that services should be coordinated among public and private agencies. (CL)

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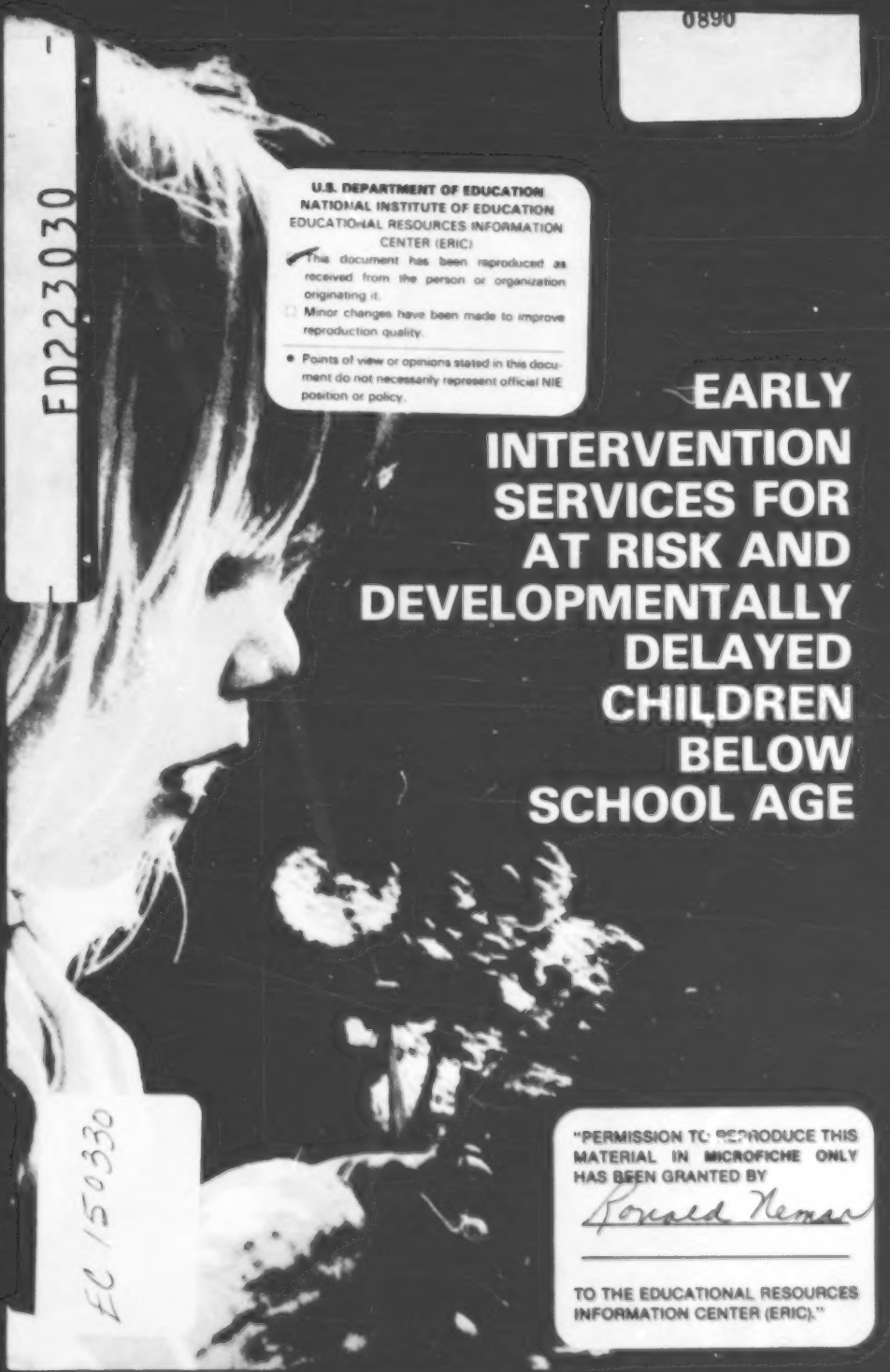
EARLY INTERVENTION SERVICES FOR AT RISK AND DEVELOPMENTALLY DELAYED CHILDREN BELOW SCHOOL AGE



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EARLY INTERVENTION SERVICES FOR AT RISK AND DEVELOPMENTALLY DELAYED CHILDREN BELOW SCHOOL AGE

POSITION STATEMENTS OF THE ASSOCIATION FOR RETARDED CITIZENS

INTRODUCTION

Research findings indicate that at risk and developmentally delayed children can greatly benefit from early intervention services, as can their parents and society. Early intervention refers to educational and related services provided to young children and their families. These services may be provided from birth for infants whose handicaps are apparent or from a point in the early months or years when significant behavioral deviations become evident. The term refers to educational and other interventions for infants, toddlers and preschoolers, and for their parents to enable them to teach their children.

Positive benefits include the prevention of secondary handicapping conditions, increased acquisition of motor, cognitive, communication, social and self-help skills, and improved integration into family life (Haring & Hayden, 1981; Haskins, Finkelstein, & Stedman, 1978; United States General Accounting Office, 1979; Zigler & Valentine, 1979). Moreover, the longer that intervention services are provided, the greater the gains (Moore, Anderson, Frederick, Baldwin, & Moore, 1979).

Additional benefits are realized by parents in that early intervention programs help them cope with their children's

disabilities and foster healthy parent-child interactions (Bricker & Iacino, 1977; Garland, Stone, Swanson, & Woodruff, 1980).

Early intervention also represents a sound economic, as well as a humanitarian, investment. Long-term studies have found that early intervention for at risk and developmentally delayed infants and young children is cost-effective since there is a decreased need for specialized programs and services beyond the intervention phase (Bronfenbrenner, 1974; DeWeerd, 1981; Lazar & Darlington, 1979; Weber, Foster, & Weikart, 1978; Weikart, Bond, & McNeil, 1978).

The term "developmentally delayed" refers to a significant deviation from the growth and developmental patterns that typically are demonstrated from birth onward. For example, the full-term infant is expected to have already developed certain basic reflexes, such as sucking, the "startle" reaction and responsiveness to sound and light. Similarly, such abilities as moving the head in order to follow objects with the eyes, achieving head balance and rolling over are expected to emerge after birth. If these behaviors are not initiated during the time span they generally appear, there is a possibility that the child may be developmentally delayed.

At risk infants include those who are premature or have very low birth weight. Or the mother's condition during pregnancy (e.g., poor nutrition, drug addiction or alcoholism) may predispose the newborn to a developmental delay. Many, but not all, of these infants test within the average developmental range at birth, but later reveal deficits in growth and development. Thus, the term "at risk" is used to describe infants and young children for whom there is a likelihood of the eventual occurrence of a handicap.

Throughout its history, the Association for Retarded Citizens (ARC) has placed a high priority on achieving appropriate and adequate educational and habilitative services for mentally retarded persons (NARC 1953, 1971, 1973, 1974, 1975, 1976, 1978; ARC, 1979). Through the continuing efforts of the ARC and other consumer and professional organizations (United Cerebral Palsy Associations, Epilepsy Foundation of America, Council for Exceptional Children, National Education

Association, Easter Seal Society, and National Society for Children and Adults with Autism, among others) a legal basis has been established for assuring the provision of educational services to mentally retarded and other handicapped persons who are six to 21 years of age. There is, however, a large population of at risk or developmentally delayed children below the age of six who are not receiving educational services due to state eligibility requirements.

In most instances, at risk and developmentally delayed infants and young children and their families do not have access to early intervention services designed to prevent or minimize the effects of developmental handicaps, including mental retardation. The ARC recognizes this serious gap in services and strongly urges that appropriate action be taken to address the early intervention needs of at risk and developmentally delayed infants and young children. In this document, the Association delineates a number of issues involved in the provision of early intervention services and presents its position concerning each issue.

ISSUE:
SOCIAL AND PUBLIC BENEFITS

Provision of early intervention services can result in important benefits to society. They can, for example, enhance a child's development and, as a result, lessen the need for highly specialized educational services or residential placement outside the natural home. These options are typically provided at rather high public cost.

POSITION:

Federal, state and local educational agencies should increase, or at least maintain, public investment in early intervention services for at risk and developmentally delayed children. Especially important is the maintenance of federal investment in programs contained in the maternal and child health

block grant and in preschool incentive grants and demonstration programs. Public support should also be maintained for research, development and demonstration programs designed to identify effective and efficient early intervention service strategies.

ISSUE:
EARLY IDENTIFICATION

The vast majority of handicapped children are not identified before they reach school, including approximately 80% of the mentally retarded population. It is critical to identify children who are at risk or developmentally delayed as early as possible in order that they can have the opportunity to participate in habilitative programs.

POSITION:

Multi-faceted screening techniques should be afforded all children at birth. Early and systematic screening of newborns should be undertaken to obtain sufficient data and information for developing prescriptive habilitation programs. The screening program should involve **at least** representatives of the disciplines of medicine, psychology, social work and education.

ISSUE:
LABELING

In identifying at risk and developmentally delayed children, early categorical labeling may lead to negative parental and professional reactions that could prevent children from receiving appropriate services. In addition, many medical and psychological tests for mental retardation and other developmental disabilities have questionable reliability when used with infants and very young children. For example, a child who is slow in crawling may be mentally retarded or cerebral

palsied or both. Of course, the child may not be handicapped at all. Frequently, it is not possible to clearly distinguish among such diagnoses in an infant even though a problem may be readily observable. However, it is not always necessary to have a definite diagnosis to begin early intervention efforts. Premature labeling based on unreliable or incomplete data and information thus can have long-term negative consequences.

POSITION:

Early intervention services should be provided to all at risk and developmentally delayed children below school age. However, categorical labeling should be postponed until there is adequate proof of a specific disability. Programs should be based on an individual's needs rather than the general characteristics associated with a specific label.

ISSUE:
ARRAY OF SERVICES

At risk or developmentally delayed children and their parents have diverse needs that cannot be adequately met by any single approach or type of service. The range of needs may be influenced by many factors, including the absence of one or both parents, the lack of adequate income to support the family, the severity of the child's impairment and the lack of respite care.

POSITION:

An array of early intervention programs and support services should be available to at risk and developmentally delayed young children and their families, including financial assistance for in-home maintenance, homemaker services, respite care, parent training and in-home and out-of-home habilitative programs. To

ensure maximum accessibility, service options should include programs which are center-based, home-based and, when appropriate, a combination of both approaches.

ISSUE:
AVAILABILITY OF SERVICES

Many families with at risk or developmentally delayed infants or young children have meager financial resources. Thus, adequate and appropriate early intervention services are often out of reach of those families due to the costs.

POSITION:

Early habilitation services should be available to all children who are at risk or developmentally delayed, regardless of their family's income level. State legislatures should be urged to adopt laws which address the developmental needs of handicapped children between birth and the state's current lower limit for school age. Such laws should be mandatory rather than permissive, i.e., the services must be available to families who desire to benefit from them.

ISSUE:
FAMILY PARTICIPATION

Most young children are a part of a family unit. There is growing evidence that family involvement in early intervention programs contributes to long-range improvements in learning and school performance.

POSITION:

Parents should have the opportunity and right to become knowledgeably and actively involved in the planning and delivery of early intervention services for their infant or young child. This

would include direct participation in all programmatic activities, professional team meetings and evaluation efforts. It should be recognized, however, that there are individual differences among families in terms of their desire and their ability to become actively involved in early intervention programs. Parents thus should have the option of non-involvement if they view this as being in their own or their family's best interest.

ISSUE:
TRANSDISCIPLINARY APROACH

At risk or developmentally delayed young children frequently present a diversity of needs. The problems associated with their disabilities do not fall solely within the purview of any one professional discipline. It is thus difficult to develop programs via service systems which are based upon traditional disciplinary channels.

POSITION:

The transdisciplinary approach is one efficient means of service delivery. In this approach, members of an interdisciplinary team teach and share their specialized professional skills with other team members. Needed services can thus be delivered without the involvement of the whole team, while the members maintain their professional and credentialed accountability.

ISSUE:
COORDINATION OF SERVICES

Early intervention services are typically provided by a number of public and private agencies and groups. In most cases, there is no single agency that coordinates early interven-

tion services to ensure that all at risk or developmentally delayed infants and young children and their families are served appropriately.

POSITION:

There should be a single state agency responsible for coordination of early intervention services throughout the state. This agency should ensure that early intervention programs are evaluated and certified in accordance with appropriate standards. Designation of the responsible agency should be at each state's option.

The ARC position statements, Early Intervention Services for at Risk and Developmentally Delayed Children Below School Age, were prepared by the ARC Program Services Committee with assistance from headquarters staff and other resource people.

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